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Article (Accepted Version)

This is a pre-copy-editing, author-produced PDF of an article accepted for publication in The Breast following peer review. The definitive publisher-authenticated version, doi:10.1016/j.breast.2014.06.013 is available online at http://www.ncbi.nlm.nih.gov/pubmed/24986765

Low Grade Ductal Carcinoma in Situ (DCIS): How best to describe it?

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Abstract (100 words)

Background

In the absence of definitive data about the natural history of DCIS the appropriateness of describing DCIS as cancer is controversial.

Methods

We conducted a survey amongst British Breast Group (BBG) members, to determine which descriptions of DCIS were deemed most accurate and appropriate.

Results

54/73 (74%) attendees completed the survey: A majority (34/54; 63%) said they would be comfortable using the description that explained DCIS as abnormal cells in the milk ducts that had not spread into other breast tissue and which did not need urgent treatment as if it was breast cancer and this description was overall the most preferred (24/54; 44%).

Conclusions

Little consensus exists regarding how best to explain low grade DCIS to patients.

Keywords

Low grade DCIS; breast screening; clinicians' views

Introduction

Ductal Carcinoma *in situ* (DCIS) is a difficult condition to define and consequently explanation of it divides opinion amongst cancer specialists.[1] It is variously described as precancerous, pre-invasive, non-invasive or intraductal breast cancer. There is debate as to whether DCIS should ever be described as cancer and this can generate confusion amongst patients diagnosed with DCIS.[2] Interview studies report that women were shocked and concerned when told they needed a mastectomy for a condition that is non-invasive[3]. Most women had not heard of DCIS before their diagnosis despite it being included in an NHS patient information screening leaflet[4].

Since the introduction of the NHS Breast Screening Program (NHSBSP) in 1988, the incidence of DCIS has increased markedly and represents approximately 20% of screen detected cancers.[5] A recent review of the NHSBSP by Professor Sir Michael Marmot considered the benefits and harms of mammographic screening and recognised that some women with screen-detected lesions are overtreated.[6]

DCIS is divided into 3 grades; low, intermediate and high. Data regarding the natural progression of DCIS is sparse, so it is nearly always treated as if it is invasive cancer regardless of grade. This over-diagnosis-overtreatment conundrum is worrying many worldwide and prompted the United States National Cancer Institute (USNCI) to suggest removing 'carcinoma' from DCIS and describe it as 'ductal intraepithelial neoplasia' instead, or even IDLE – InDolent Lesion of Epithelial origin.[7] More recently the National Institute of Health (NIH) convened an expert group in 2012 to provide other suggestions. There was a consensus that antiquated nomenclature such as DCIS needed updating and thresholds for what should be regarded as abnormal raised.[8]

A DCIS diagnosis can be perplexing as well as distressing for patients; often they are told that they may have a very early form of breast cancer that needs immediate treatment in the absence of any apparent tumour. Treatment may include mastectomy, confusing women even further especially if they know of other patients with manifest invasive breast cancer who only require a wide local excision. It can appear illogical to have no lump but 'very early breast cancer' that necessitates mastectomy[3]. There are trials being conducted worldwide that aim to measure the outcome of different management policies for low and low/intermediate grade DCIS. It is vital to ensure that all recruiting clinical teams are comfortable when describing low grade DCIS and that women receive consistent information. A randomised trial of surgery versus active monitoring for LOw RISk DCIS (LORIS)[9]. has recently been launched in the UK. We wished to determine which descriptions of DCIS would prove most acceptable for use in trial literature and when discussing the trial with women.

Methods

Design

We designed a questionnaire based survey eliciting the views of breast cancer experts about how best to describe low and low intermediate grade DCIS to patients.

The Questionnaire

First we conducted an Internet search eliciting the many different but commonly used descriptions of DCIS: these were reviewed by three researchers. Four descriptions from high profile cancer charity websites (Macmillan, Cancer Research UK (CRUK), Breast Cancer Care and Breast Cancer Campaign) were chosen as they are all well-known and trusted amongst the general public. The descriptors were mainly found under the heading of: "What is DCIS?" and usually provided a summary of DCIS with further information on the website under other sub-titles. The way in which DCIS was described differed substantially, for example one said DCIS was the earliest possible form of breast cancer whereas another said that it can be described as pre-invasive, intra-ductal or non-invasive cancer. Members of the LORIS trial team created a fifth description, which we considered provided a more balanced and accurate description of DCIS. Table 1 shows the final five DCIS descriptors used.

To avoid any biases the survey descriptors were not labelled with their source and were presented in a counter-balanced order to avoid all respondents being exposed to the same descriptor first, thus five versions of the questionnaire were produced. Respondents were initially asked if they would be comfortable (yes or no) using each descriptor when talking to patients about low and low intermediate grade DCIS. They then indicated their most preferred and most disliked descriptions. If respondents disliked all options provided they were invited to write their own DCIS description.

Results

Respondents

The paper-based survey questionnaire was completed by 54/73 (74%) healthcare professionals attending the British Breast Group meeting in February 2013, 35 males (35/54; 64.8%), and 14 females (14/54; 25.9%). The different professional disciplines included surgeons (22/54; 40.7%), oncologists (13/54; 24%), radiologists (7/54; 13%), scientists (7/54; 13%), pathologists (3/54; 5.6%), an endocrinologist (1/54; 1.8%) and a cancer geneticist (1/54; 1.8%).

Table 1 shows the proportions of respondents who would feel comfortable using different descriptors with patients. Most appeared comfortable with that devised by the LORIS team 34/54 (63%), followed closely by the CRUK description (29/54; 54%).

Respondents (36/54; 66.6%) were least comfortable with the Macmillan description. This was mirrored across all professional groups, with 70% (14/20) surgeons, 85% (6/7) radiologists, 66.7% (2/3) pathologists and 75% (9/12) of oncologists.

If respondents were not comfortable using any of the five descriptors they provided their own. Analysis of this free text showed the division of opinion about DCIS as cancer e.g. one surgeon wrote:

"I say it is pre-cancer and it can become cancer if left behind"

Whereas another stated:

"You need to emphasize it is not cancer"

Seven of the 10 wrote their own descriptions, broadly mentioned DCIS as not life threatening and three stated that DCIS was cancer. Four stated that if DCIS was left untreated it could turn into an invasive breast cancer. Four respondents said they used diagrams and similes when discussing DCIS with patients.

Table 1 also shows the most and least preferred descriptions; 3 respondents had no preference and 3 chose two.

Most preferred was that devised by the LORIS Team; (44%; 24/54). This was independent of professional group or sex. It was preferred by 67% (14/21) surgeons, 86% (6/7) radiologists, 33% (1/3) pathologists and 58% (7/12) oncologists.

Discussion

Definitions of DCIS available on the websites that patients might access are inconsistent. The results of this survey amongst breast cancer specialists, demonstrate that it is a difficult condition to describe. There is particular disagreement amongst experts about the use of the word cancer.

It is common for patients to consult the internet for more information about their diagnosis. Prominent and well publicised cancer charities are trusted and often accessed first. This survey showed that descriptions used by breast specialists and those found on charity websites vary creating difficulties for patients and doctors treating them if terminology used is inconsistent.

The Cancer Research UK (CRUK) description of DCIS was the longest used in the survey; (a couple of respondents commented that it was too lengthy), but it does have a very clear diagram showing the difference between DCIS and invasive breast cancer. Using diagrams to explain difficult concepts are often helpful and a few of the respondents surveyed said that they like to use diagrams when explaining DCIS to a patient.

The least preferred descriptor from Macmillan was the briefest, however none of the respondents of the survey made comments about its brevity. Importantly since our survey was completed Macmillan has updated their website extensively, with very comprehensive information about DCIS and diagrams of normal cells and cells forming a tumour. The Breast Cancer Care website has a useful 12 page booklet providing information about diagnosis, treatment and different grades of DCIS that can be downloaded or hard copies ordered. The main body of their text used to describe DCIS has remained unchanged to that used in this survey.

Breast Cancer Campaign's website description is the same as that used in the survey and includes information about research they fund including the genetics, biology and spread of DCIS as well as the emotional impact of a diagnosis of DCIS for women.

The LORIS description of DCIS was preferred regardless of gender and across all clinical specialties; importantly 63% of respondents would feel comfortable using it even if it was not their preferred description. The LORIS team comprised a surgeon, oncologist, trials co-ordinator and two psycho-oncologists who elicited views from a variety of sources including patients as to the most user-friendly, accurate and informative means of describing DCIS without mentioning phrases such as early form of cancer.

Most survey respondents were clinicians who have to discuss the diagnosis of DCIS and its management with patients. Different results might have been obtained if the survey had been conducted with more pathologists.

The LORIS trial opened June 2014 and is accompanied by a patient friendly information DVD that uses the most preferred description found in our survey. Healthcare professionals should also check that the websites that they suggest patients might access for further information is congruent with what has been said in clinic.

Although the results of our survey were limited by the small sample size we hope that they might contribute to the ongoing debate as to how DCIS is best described. Patients with low grade DCIS cannot make informed choices about trial entry or treatment without consistent information.

Conflict of interest

All authors are actively engaged in the LOw RISk DCIS trial

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Appendix A: Web addresses of cancer charities

http://www.macmillan.org.uk

http://www.cancerresearchuk.org/cancer-help/type/breast-cancer/about/types/dcis-ductal-carcinoma-in-situ

www.breastcancercampaign.orghttp://www.breastcancercampaign.org/about-breast-cancer/breast-screening/ductal-carcinoma-in-situ

http://www.breastcancercare.org.uk/breast-cancer-information/about-breast-cancer/primary-breast-cancer/types%C2%A0of%C2%A0primary%C2%A0breast%C2%A0cancer/ductal-carcinoma-situ-dcis

Table 1 Summary of main results

Description	Comfortable Yes N(%)	Comfortable No N(%)	Most Preferred description N(%)	Least Preferred description N(%)
LORIS TMG: DCIS stands for 'Ductal Carcinoma in Situ' and means that there are abnormal cells in the milk ducts of the breast. This has not spread into any other breast tissue. Before breast screening took place a diagnosis of DCIS was rare but now it is common. DCIS looks like specks of white (calcium) on a mammogram. When doctors look at DCIS under the microscope they can split it into different grades – high, intermediate and low. High grade DCIS cells look more like invasive breast cancer cells. Because high grade is more likely to turn into breast cancer, it is treated as though it is. Many doctors are uncertain if low or intermediate DCIS would ever become invasive breast cancer. Some feel that it needs watching, but doesn't need urgent treatment as if it was breast cancer.	34/54 (63)	18/54 (33)	24 (42)	6 (11)
Cancer Research UK: If you have ductal carcinoma in situ (DCIS), it means that cells inside some of the ducts of your breast have started to turn into cancer cells. These cells are all contained inside the ducts and have not started to spread into the surrounding breast tissue. So, there is very little chance that any of the cells have spread to the lymph nodes or elsewhere in the body. Doctors use various terms to describe DCIS, including pre invasive, non-invasive, or intraductal cancer. Your doctor may describe DCIS as a very early form of breast cancer. If it is not treated, in some women DCIS starts to spread into the surrounding breast tissue after some years. So it may become an invasive cancer. DCIS is being found more often than in the past. It is sometimes picked up by mammograms when women are screened for breast cancer. Nearly 4,650	29/54 (54)	22/54 (41)	16 (28)	7 (13)

women are diagnosed with DCIS in Great Britain each year. DCIS and invasive ductal breast cancer are not the same thing. In invasive ductal breast cancer, the cells have broken out of the ducts and spread into the surrounding breast tissue. There is then a chance that the cells can spread into nearby lymph nodes or other parts of the body				
Breast Cancer Campaign: DCIS is a non-invasive type of breast cancer which is confined to the breast's milk ducts and has not spread into the surrounding breast tissue. We don't know enough about the condition to reliably predict which cases of DCIS will progress to invasive breast cancer, and therefore debate has arisen about its routine detection and treatment. The detection of some cancers which may not cause harm to women in their lifetime, for example Ductal Carcinoma In Situ, or DCIS is often discussed in relation to over-diagnosis of breast cancer.	19/54 (35)	32/54 (59)	7 (12)	9 (17)
Breast Cancer Care: DCIS is an early form of breast cancer, where the cancer cells have developed within the milk ducts but remain there 'in situ' having not yet developed the ability to spread outside the ducts into the surrounding breast tissue or to other parts of the body. You may hear DCIS described as a pre-invasive, intraductal or non-invasive cancer. Occasionally you may also hear it incorrectly described as pre- cancerous. Both men and women can develop DCIS, however it is very rare in men. As a result of being confined to the breast ducts, a diagnosis of DCIS has a very good prognosis (outlook).	23/54 (42)	29/54 (54)	4 (7)	8 (15)
Macmillan: Ductal Carcinoma In Situ (DCIS) is the earliest possible form of breast cancer and is non-invasive. Although DCIS needs to be treated, it isn't a life-threatening condition. Surgery is the most common treatment.	15/54 (27)	36/54 (66)	3 (5)	17 (32)
Total			57* (100)	54 (100)

***Total of 57 as 3 people had more than one preference